

FAMILY CARE COUNCIL FLORIDA

PATTY HOUGHLAND, CHAIRPERSON

Hampton Inn Orlando Airport

Orlando, Florida

September 16th, 2006

MEMBERS PRESENT:

Patty Houghland, FCCF Chairperson
Bob Wessels, FCCF Treasurer
Ann Millan, FCCF Past Chairperson
Joy Frazier, A1 Chair, FCCF Secretary
Frank Carroll, A3 Representative
Beverley DeStories, Suncoast Region 5 Chair
Maryellen Jones, A9 Chair
Belkis Almeida, A10 Co-Chair
Betty Kay Clements, A13 Chair, FCCF Vice Chair
Sara Howerton, A14 APD FCC Liaison

STAFF & GUESTS

Stephanie Khan, APD Central Office
David Alexander, APD
John Hall, ARC Florida
Lynn Carper, A1 Guest
Dean & Louise Parker, A4 Guests
Amelia Rauber, A7 Guest

The mission of the Family Care Council Florida is to advocate, educate, and empower individuals with developmental disabilities and their families, partnering with the Agency for Persons with Disabilities, to bring quality services to individuals for dignity and choice.

I. CALL TO ORDER

Chair Houghland called the meeting to order and welcomed everyone. She explained there are 2 information packets. The blue folder is FCCFlorida information which will be referred to throughout the meeting and the red folder is information supplied by APD Central office and will be addressed either by Denise or Stephanie. Chair Houghland asked for introductions to include area FCC represented. Joy asked that everyone remember to fill out the evaluation survey before leaving today. Bob advised he has 5 of the law enforcement video tapes left for anyone who hasn't already received one or has use for a second one.

II. WORKGROUP REPORT

Chair Houghland made reference to the workgroup meeting that took place the day before.

Issues discussed included:

- **The DOAH (Dept. of Administrative Hearings) vs. Fair Hearing issue.** APD has petitioned the commission requesting to allow the agency to ignore the Court's decision and continue fair hearings as the only alternative until at least 90 days after the upcoming legislative session. The whole conversation of the workgroup revolved around the fact that we need the system to be a fair system which they don't feel it is now. The workgroup realized they are not in a position at this time to make recommendations of what would be a fair system. John Hall will provide some conversation about this issue during his presentation. Chair Houghland shared that in the packet of information is a copy of John Hall's E-mail on the subject and a copy of the APD's petition. Bob mentioned in the petition the agency indicates it has an average of 100 fair hearing requests a month.
- **CORE Re-write** – Chair Houghland sent out via E-mail for the chair's review. The agency is asking for comments by September 22nd. Beverley and Frank have volunteered to review the document and make comments. Chair Houghland requests that they forward the comments to Linda Mabile. Frank suggested sending his

comments to Beverley so she can add to her comments and form one document. Chair Houghland asked the document be copied to her and Betty Kay.

- **FCCF Website and Waitlist** – Ann advised they discussed the issue of Foster Care individuals now being added to the top of the waitlist. They shared their concern for these individuals but Frank added our concern should be for all the individuals on the waitlist. That is the priority. They are thinking about creating a section on the FCCFlorida website devoted to stories of individuals who are waiting for services. The stories would be short, similar to celebrate employment book, a bio type thing. They could keep track of the list and create a booklet to show to the legislature that the individuals on the waitlist are the priority. This allows for a face and name rather than just a number.

III. BUSINESS

Review of Minutes – Chair Houghland mentioned she did not receive any corrections to the July minutes. She asked Donna if she received any. Donna replied no. Chair Houghland asked for a motion to accept the minutes as submitted. Beverley makes the motion. Frank seconds the motion. The minutes were approved by consensus.

Treasurer's Report – Bob advised they do not have a report yet. It's not because either he or Stephanie haven't tried. It's the state government system they're dealing with. He reviewed that each area FCC has received \$9,500. Suncoast Region received \$19,000. Area Seven's additional transfer of \$500 has been booked. Area 10 has agreed to transfer an additional \$500, Area 1 an additional \$1,500, and Area 9 an additional \$1,500 (Maryellen thinks that is the amount). Those transfers have not been booked as yet. Bob reminded everyone that it's the responsibility of each FCC chairperson for overseeing their area's expenditures either by working closely with their area FCC liaison, financial person or AA. Bob mentioned the FCCFlorida year to date expenditures total \$1,600 which covers the travel and meeting accommodations for the July meeting. Maryellen asked Bob for the name of the APD form. Bob replied it's the Budget Transfer Request (BTR) form. Bob mentioned he would send out a copy of the form via E-mail. Stephanie advised the area FCC liaisons submit the form. Ann mentioned it was discussed the day before that the chair's need to ask the liaison's for a copy of the form when submitted. Chair Houghland advised next FCCFlorida meeting will be November 17th and 18th at the same location. She mentioned they are no longer locked into the current location for the rest of the meetings. They can research other locations but emphasized they will be staying in the same complex because of its convenience to the airport.

Old Business – Frank mentioned he is returning the 24/7 tape. Joy will pass along to the next person on the list.

Ann mentioned she wants to add to the website a section titled "Consumers Corner". If anyone has any powerpoint done by a consumer, their person centered plan, a story they want to do about employment or any other consumer suggestions please let her know. Ann shared her thank you to Maryellen for providing dinner to Robin and 24 people attending the ASPE conference. She mentioned they all had an incredible time.

FCC Updates – Chair Houghland asked if chairpersons or representatives have anything they would like to share.

Area 9 – Maryellen shared that Catholic Charities in Palm Beach County who owns and operates three group homes with a total of 18 residents tried to close them down. She was asked by the area nine administrator to be the advocate for the individuals in the group homes, attend the meetings and make sure their best interests were upheld. She shared a group of people picketed in front of the group homes which made their local newspaper. Through numerous negotiations with people, various organizations and the Roman Catholic Church they were able to have the owners back off. Ownership of the three homes has been transferred to a parent organization

called Friends of Nazareth Homes and Sunrise organization will manage the homes. It has been written into the contracts that these 3 homes will always be group homes.

Area 14 – Sara Howerton shared their FCC has invited Lynn Hamilton, a parent of a person with autism, who has written a book and is a nationally recognized speaker to present at their workshop on October 7th. They are also working on establishing a guardianship forum with legal representation. It's an ongoing concern for many families in their area. Sara shared with everyone in attendance a couple of helpful booklets, one titled "About Raising a Child with a Disability" the other titled "About Being Sensitive to People with Disabilities".

Guardianship – Bob shared a grant awarded by the DD council is providing three guardianship forums in Ft. Lauderdale, Tampa and Tallahassee. It's a 2 day conference, the first day for attorneys, the second day for families. FCC co-chair Jean Sherman is the chairperson of the advisory committee working on the grant. Chair Houghland hopes that included in the material covered is less restrictive alternatives to guardianship. Betty Kay indicated the primary focus is on guardianship advocates as defined in Chapter 393. They hope to educate attorneys because most are unaware of the guardian advocate statute. Chair Houghland cautioned that if you're in the presence when guardianship is the issue, be sure to ask the question is there something less evasive that could be considered or learned about besides guardianship. There are other options available besides taking rights away to protect the person because that's really not protecting, it can be very detrimental.

Area 1 – Joy shared they have invited Joseph Meaders, a self advocate who has written a book on relationships, dating, friendships, and sexual issues, to present a workshop on sexuality at their next meeting. They are currently working with their area office to clean up and revitalize a park ravaged by hurricanes in a neighboring county along the banks of the Black Water River. It will have accessible docks for fishing and picnic areas. They are hoping in the future to offer summer programs for individuals with disabilities.

Area 10 – Belkis mentioned that in her area the information line 211 has added a special needs hotline. When you call the number you immediately get a message that if you have a child with disabilities dial 6. They have 2 well-informed counselors on staff designated to take those calls. They are really working hard to develop a database of the resources in the area that can be of assistance to families of children with special needs. She shared it's being funded by the Children's Services Council. Beverley shared that her last day with FND is Friday. She has been hired as the resource coordinator for Citrus and Hernando Counties with 211 Tampa Bay Cares which was formally United Way. Her job will be similar to what Belkis has shared.

Upcoming Conferences - FASC (Florida Association of Support Coordinators) has asked Family Care Council Florida to do a break-out session and display at their annual conference. Chair Houghland accepted the invitation and has asked Ann and Betty Kay to take the lead on this. It will take place the October 11th – 13th at the Ocala Hilton Hotel. Ann mentioned she is planning on talking about teamwork and everyone working together.

TASH Conference will take place November 8th – 11th in Baltimore Maryland. Chair Houghland mentioned this is always a very good conference. She realizes that council money is very tight but is hoping that maybe one person could attend to bring the information back. They estimated the cost would be about \$1,000 which includes registration fee & travel expenses. Frank suggested that possibly one council might have money left over they could donate to FCCFlorida. Ann mentioned that maybe APD could get a reduced rate on registration since it's state funds. Chair Houghland emphasized it's a wonderful conference and hopes someone within an area FCC or FCCF can attend.

Chair Houghland mentioned she is attending, on behalf of the Advocacy Center, the National Conference on Home and Community Based Waivers in Minneapolis, Minnesota in October. She is hoping to bring back a lot of good information on how other states are dealing with crises through the waiver and Medicaid Reform.

Inactive Family Care Councils – Beverley and Ann shared the many issues going on within Suncoast Region APD office and trying to re-start the Suncoast Region East FCC which has been inactive for some time. Beverley is experiencing many roadblocks with FCC liaison and administrator. The issue needs Central Office assistance. Chair Houghland suggested she would talk to Denise and see if arrangements could be made for Stephanie, FCCF Liaison and FCCF chairperson go to the Suncoast Region program office to offer their assistance in getting the problems solved. They may also need to spend some time in Area 4 and Area 2. Stephanie mentioned she and other personnel are currently working on updating the FCC orientation manual and training for FCC liaisons. Frank asked if parents and FCC members are being contacted to help with coordinating what information is included in the manual. Currently no but Stephanie advised it's a work in progress. Chair Houghland mentioned it has been discussed that FCCFlorida needs a very strong and a lot of time from our FCCF liaison. She will remind Denise of this at a later time. Issues such as the manual need direction, time and FCCF input.

IV. APD UPDATE – Denise Arnold, Chief of Community Development

Chair Houghland welcomed Denise via teleconference call. She mentioned they would begin with questions previously sent to Denise. Ann began with 2 questions not on the list.

- Was there a method of zero tolerance in process when the WSC event was settled, happened or identified in District 15? Denise advised in was definitely in place at that time and still is. They have to go through the abuse reporting process which encompasses dealing with another entity that do the interviewing. It's an unfortunate situation but luckily they did get to the bottom of it. Those type issues are not easy to fix or easy to find out the facts.
- What is the update on CAFÉ? Denise advised APD is not funded like they were last year for CAFÉ. Unless they receive some funding, there isn't much they can do about it. She mentioned they are looking at other alternatives to tag onto some of their grants such as the Quality Management grant where they have some symposiums they could sponsor as a way of offering some more local educational opportunities. They haven't gotten very far on any plans or discussion. She indicated that in the future they would talk with FCCF to include any suggestions or help from the council. She said it's up to the legislature, if they come up with funding, CAFÉ would continue.
- Is the crisis criteria to be more inclusive for the elderly with their individuals still living at home? Denise advised the criteria for crisis is still the same. The only change that will happen sometime this year is the legislative session has given APD the authority to write rule about crisis enrollment which includes application and eligibility. Currently crisis is defined in Appendix F of the HCBS handbook. Appendix F is really a rule through Medicaid. It's intended to be a provider handbook. What will happen soon is they will file some sort of rule to take that into APD's realm and Appendix F will be removed from the handbook. Denise believes this is a good thing as APD needs authority to develop those rules. Ann asked how many people are being approved monthly for crisis. Denise believes about 50 per month. The money has to be there before they can approve crisis. Ann asked if they were all going on HCBS or some to FSL. Denise didn't have numbers per waivers but would get for the council. Ann requested that FCCF be included in the rule making process. Denise agreed.
- What is the status of the Family2Family grant? Denise will E-mail some information Marjorie prepared for her regarding this project. She mentioned brochures have been prepared to be sent to the pilot areas (Duvall, Gadsden, Polk, Broward and Hillsborough). They are trying to arrange some meetings in Gadsden County for families that will include educating them on resources available, offer opportunities to become better self

advocates, speak out in community meetings and do some mentoring type programs. They sent 70 brochures to Gadsden County families and 8 responded. Ann asked if Stephanie could get some brochures and send out to council chairs. Denise replied yes, definitely.

- Business Leadership Network – Denise mentioned that included in the APD information packet is a summary update of APD’s 5-Year Employment Initiative. She advised they are planning on increasing the number of BLN’s in the state. The Medicaid Infrastructure grant helps support that. They have applied for a second year. Ann expressed concern with how the projects are being run and if any monitoring is being done to determine if we’re getting our money’s worth. She knew of a meeting in Tampa but couldn’t get confirmation from anyone as to when or where. She asked someone from One-Stop if he was planning on attending. He didn’t know what she was talking about. Ann emphasized they have an excellent community relationship with businesses that don’t mind donating for those individuals with developmental disabilities but it doesn’t enter their minds they could hire them. These people should be included in BLN’s meetings. Denise advised she would write up a summary of FCCF concerns that can be shared with Leslie Wilson. She indicated it is a wonderful tool and they are getting a lot of people hired through the process.
- Travel – Denise was asked if she found any additional funding for FCCF travel. Denise asked about it but was told it’s not something you can move to the way FCCF budget is funded. She said it doesn’t mean they can’t find something but it just may not be right now. The other concern is that some people still have an impression (some true) that FCC’s don’t spend their current money and where is the justification for more. Denise did speak on behalf of the councils that they are doing a much better job of spending their money. Maybe if the councils know of a particular conference they would like to attend some grant monies could be found to help with the travel expense. Ann mentioned how the council would like to send someone to the TASH conference. Denise suggested sending someone, pay for it and if down the line you run short she’ll see if there is some way they can help with travel to other functions.
- Does APD have any plans to reprint the FCC booklet? Denise mentioned previously she had talked to the council about improvements to the Application and Eligibility process. They have updated the policy and changes reflect input made by FCCF. Once the person becomes eligible a letter will be sent to them which will include a paragraph or reference about the Family Care Council. Instructions to the area offices will include asking them to meet with FCC to secure brochures that can be included with the letter. She would like to see the FCC booklet (see needs to review again to check for any additions or deletions) sent along with the letter. Ann mentioned FCCF has commitments to participate in some conferences such as FASC but have no handouts at this time. Denise advised she would get on this, review it, have Terri and others review. The council is requesting funding for printing the FCC booklet through APD. Ann previously sent Denise a quote for 10,000 copies at approximately \$2,000. Denise will follow through on this.
- Chair Houghland asked if anything has happened with regards to the meetings held on the SIS (Support Intensity Scale) issue. Denise indicated no and whatever happens will take some dollars whether it be fixing the current ICG or purchasing the use of another tool. The current problem is figuring out a good assessment tool. They have reviewed the Georgia tool and Gary Smith will be sending them a report he is has compiled on a variety of assessment tools. Currently there isn’t a tool that provides a connection to budget ranges. She said if they can get to that then more flexibility can be provided within the amount of dollars someone has in their cost plan to move money around. She

mentioned they would share the report with the council. Chair Houghland asked if there was any time element on this. Denise replied no, not really. No new dollars were budgeted to cover the cost of a new tool in the upcoming year.

- What is the latest on updating the HCBS handbook? Denise mentioned what they are trying to do with the handbook is prioritize what to change first. They are reviewing all the comments submitted previously and pair down their first rollout. She made reference to a couple of the changes and advised she would send Chair Houghland a written copy of the list.
- There is a problem with sending and receiving CDC time sheets by fax. Is there some way the fiduciary can E-mail or contact the Florida consumer rep. that the time sheet has been received? Denise advised not in the current system. They have awarded a new fiscal agent (Public Partnerships) but they don't have a negotiated contract yet but they will. One of the key elements will be notification, time sheets being one of them. Frank explained the problem which has a lot to do with holidays. Denise agreed it's a major problem and will re-visit the issue to see how it can be worked out.
- Has the legislative dollar increases for providers and WSC been implemented yet? Denise advised yes, it's going pretty good. There was a problem with WSC's but it has been worked out.
- Is there any money for people on the waitlist? Denise advised no with the exception of the children in community based care (foster children). Proviso language and statute change identified foster children after crisis as the priority. Chair Houghland asked since crisis is funded throughout the year or until maxed out, when do they go to community based care and pick up those children. Denise advised they are in the process of doing data matches with the child welfare system. The projections included 300 – 350 people. Once they have those names, they'll be sending offers for enrollment. She was asked will it be the HCBS waiver. Denise replied it would probably be the FSL waiver.
- What is the latest with the pilot of the new support plan format? Denise mentioned they are still working on it. They have slowed down on their eagerness to implement it because of the provider rate increase. They are hoping to implement sometime after January, 2007. She indicated they are having a meeting on September 28th from 10:00 – Noon with the company doing the pilot. Chair Houghland asked if FCCF could be included either at the meeting or by phone. Denise advised yes.
- What is the latest on the FDDC's efforts to evaluate Medicaid Reform? Denise mentioned they did put out some information which she'll try to pass along to Chair Houghland. She pulled up the FDDC legislative platform which includes a good summary identifying what they think the system should look like.
- Will there be money available for employment stipends for individuals? Denise advised the only money they received was part of the IFS dollars to continue supporting those people that were started last year. Nothing new beyond that.
- How does the quarterly budget report to the legislature look? Denise mentioned Stephanie provided a copy of the quarterly report in the APD information packet. She reviewed the document with the council. Ann asked for verification on Table 5: Waiver Enrollment Summary. It indicates 11,204 people were offered services. Of that only 6,566 are enrolled. Is that a correct figure? Denise advised yes. There are a variety of reasons why they were not enrolled. Joy asked if any thought had been given to discussion at previous meeting that maybe some of the reasons for families declining is their lack of education and understanding what's available to them. Denise advised yes and it's a good suggestion to provide some type of educational meeting to families once they have been offered enrollment. They would like to incorporate that into the

enrollment process sometime in the future. She thinks for the time being the FCC brochures and FCC bulletin will be helpful to families. Discussion followed regarding contact insert card the council suggested including in the FCC bulletin. Denise asked someone to provide her with a draft card. Ann asked what APD was doing with the CHAMPS 1-800 number. Denise replied not much. Ann mentioned FCCF would like to have it. Denise advised she would have to meet with others internally and would see what could be done.

- When a child is 3 and apply for services are there policy/procedures as to what the APD will accept as documentation of a disability? Denise advised yes and she can send Chair Houghland a draft of the procedure which is currently being reviewed by their legal staff. She mentioned the Support Coordinator's handbook also as the criteria.
- Has any decision been made regarding FCCF's recommendation to request a person receive a POM review? Denise advised she hasn't had a chance to discuss with Kerry or Shelly yet but doesn't see a problem. She believes criteria, guidelines and a referral form need to be initiated. She summarized the draft which was discussed at previous FCCF meeting. She will see that the draft is sent to Chair Houghland next week. They are open to any additional suggestions from FCCF.
- What is the latest on the Legislative Budget Request (LBR)? Denise advised Shelly is meeting with the Governor along with other agency directors over the next few weeks to review the LBR. She believes they are still in discussions about what has been submitted. She mentioned the FCCF request for funding to cover an executive director in the amount of \$50,000 was not included. Shelly didn't feel the legislative support was there.
- Is the CDC+ grant up in March, 2007? Denise advised no, it's March, 2008.
- How many individuals have signed on for the Florida Freedom Initiative? Denise advised 21. One of the challenges is making sure they have good benefits planning for these people. They do have other people interested in the program. It was shared the many issues that make the program very complicated.
- Beverley asked Denise what is the necessity of an individual that is going to serve as a chairperson or member of an FCC to reside in that physical location. There is a situation in Suncoast Region with East and West whereby the area administrator has nullified the existence of members in the East region because none want to become chairperson and they don't have the numbers. The liaison hasn't sent in the FCC applications for those who have applied. One new applicant, a former member of the West council, has volunteered to serve as East chairperson and mentor individuals to build up the East council. The liaison has declined the application because the person doesn't live in one of the East designated counties. Denise asked Stephanie to put on the list for her to contact the area administrator to see what can be done to solve this problem.

Chair Houghland thanked Denise for her time and assistance.

V. PRE SERVICE TRAINING FOR SUPPORT COORDINATORS – David Alexander
Chair Houghland introduced David. He is currently working on establishing a new curriculum for support coordinators. David has provided everyone with copies of 2 sets of curriculum and would like the council's input. They are considering a curriculum made up of 2 phase training modules. Phase one is what they currently call the state pre service training (handout titled Curriculum Outline Before Getting Up and Running). Phase two is the handbook titled Curriculum Outline Getting Up and Running. He isn't sure the titles will remain as they are at this time. David reviewed the modules and explained the information included in each. He mentioned this training is not for CDC+ consultants, they have a totally separate training

program. The training focuses on HCBS and bringing in the parts of FSL that are different. These modules will make up the trainer's manual. It will not necessarily be what is distributed to the participants at trainings. Chair Houghland mentioned one of the things missing in support coordination mentality is the value of being connected to the community and how that is supposed to happen. She is hoping this will be included in the training. David shared that back in 1993 SC's wrote support plans which included this is the person and this is what the person wants. There was no focus on who pays for it until after the fact. Now the whole focus of the support plan is what is paid services through the waiver. If it's not a waiver paid service then the SC doesn't need to talk about it or write it down. David advised that is not true. Everyone agreed with their applause. David shared that he has added something to the training modules that hasn't been there before. It's a section on Hiring/Monitoring Providers. It will include a handout SC's can give to families that teaches the families how to set up a code of ethics with your providers, how to talk to them about what you like and dislike about what they are doing and learn how to negotiate and talk about any problems that exist. Chair Houghland asked if it was written to be consumer friendly. David advised yes. The manual will be developed as a work that is always in process because of all the APD changes that occur. Ann asked if under the category of guardianship if client advocate has been included. David replied yes. David explained he is a huge believer in informed choice. Discussion followed expressing the importance of allowing individuals to take risks, if they fail, offer guidance that will allow the person to learn from the occurrence rather than scolding or not giving them an opportunity to try again. Beverley mentioned that so many of the fair hearings utilize documentation that is not done appropriately to indicate medical necessity. Many people have lost their hearings because of inappropriate documentation. Will this be addressed within the documentation giving SC's positive examples of how to document to the benefit of the individual? David replied yes. Discussion followed with examples of how documentation is done inappropriately by service providers and whose responsibility is it to tie all the documentation together. David replied it would be the SC who receives all the documentation from service providers prior to package being sent in. The SC needs to be trained well enough or know his/her client well enough to determine if the documentation is accurate for that individual. David indicated FASC is allowing for the first time providers to join and participate at the annual conference. They will have some breakout sessions specifically for them. Providers can become members but without voting rights. Ann asked if there was anything on monitoring the annual support plan. It's not a matter you write in July and then forget about until the next year. It's a matter of monitoring the services and programs on an ongoing basis to make sure the support plan is being followed. David replied yes, it falls under module 6. Ann mentioned she hears all the time that SC's don't know the definitions of the services in the handbook. David agreed. He has emphasized during his training that the handbook is the SC's bible. They need to read monthly. If the SC doesn't understand what the handbook has to say about each service, how can you monitor what is going on with the service or know what services to recommend to the individual. Discussion took place with regards to the changes in the fair hearing process. David explained his understanding of the different time elements per notices involved. John Hall mentioned some issues that didn't support David's understanding that he had learned just a few days before from P.K. Jamison, APD general counsel hearing officer. In summary, it's still a work in progress. Chair Houghland thanked David for his time and allowing the council members to provide input. David shared he really appreciates the feedback received from everyone.

VI. LEGISLATIVE ISSUES - John Hall, Executive Director - ARC Florida

Chair Houghland introduced John and advised he would be presenting to the council two issues, one being ARC Florida's legislative platform for 2007 session and the other regarding fair hearing petition.

Legislative Priorities – John passed out draft copies of the proposed legislative priorities for the 2007 session. He advised the board has not signed off on it as yet, but the governor affairs committee has. They have a board meeting on September 25th to finalize the document. He reviewed and provided comments on the following priorities:

- **Fully address the needs of people with development disabilities, especially those on the waiting list.** He was surprised to see the report that there are 17,000 on the waitlist now. Of that number 6,600 are on the FSL but still they remain on the wait list for all their medically necessary supports. He mentioned he understands that some legislators have asked APD people how much would it cost to serve all the individuals on the waitlist. They don't get an answer. He suggested FCCFlorida might want to ask that question. He commented on the bulleted items under this category.
- **Improve continuity of service and care coordination in the Early Steps program (Part C) and provide the much needed funding for the program.** John mentioned ARC Florida believes families and taxpayers would both benefit if this program was transferred to APD. He was asked why? He replied currently there are 2 evaluations, one for Early Steps, then when aged out of that, another evaluation takes place. Also, support coordination, etc. starts over again. Families prefer to have an SC that stays with them. It would be more cost effective to have the program in APD. Also they are requesting increased funding to the appropriate level necessary for significant development gains and other important benefits for children and their families. John was asked to develop a fact sheet with information to support this issue. Early Intervention is extremely important.
- **Design and fund a statewide network of public emergency shelters for people with disabilities.** Acceptable shelters with appropriate levels of support and services are needed for Florida's individuals with developmental disabilities during storm and similar emergency situations. Most public emergency shelters won't accept individuals with disabilities. Also, individuals with significant disabilities including the use of oxygen and other healthcare needs have few to no options available to them. This includes individuals with behavioral issues who can't deal with confining situations. Discussion followed expressing viewpoints on the need for such shelters in the state. John mentioned one of the main concerns is people in supported living who need assistance but no one to help them. Joy emphasized the need for regional shelters rather than just one statewide. Sara mentioned in Area 14 they do have a disaster plan that must be filled out for all their individuals in supported living. The area office must have a copy on file. John suggested FCCFlorida include this issue in their legislative platform. The Office of Homeland Security has a lot of money and could fund this type of shelter.
- **Improve the capacity of Public Guardianship and Guardian Ad Litem services for people with disabilities.** John shared he has met twice with APD on guardianship issues. Included in the meetings have been representatives from State Office of Public Guardians, Guardian Ad-Litem, APD and Advocacy Center. P.K. Jamison, APD legal counsel indicated they are looking to find the number of people who have already been adjudicated whose guardians have died or left the state leaving them with no guardian. They believe there could be a couple hundred people. APD, along with ARC Florida & other organizations are looking to secure money to arrange for public guardians for these people. John stressed the need for guardianship education especially the medical aspects to be included for families & individuals within the special education, high school programs. Discussion followed providing examples of the need for better education as many parents still don't understand they aren't automatically the individuals guardian throughout his/her life. They lose that right when the child turns 18.

- **Additional Issue for Legislative Consideration** - John reviewed a few of the issues which are found on the back of the priorities sheet. They include the need to establish an income limit for eligibility under the Medicaid Waivers that is equal to the Medicaid threshold, expand the services available under the FSL waiver and conduct a capacity study and needs assessment of Speech, Occupational and Physical therapy services. Maryellen mentioned she learned at the ASPE conference that Shelly Brantley no longer wants to use the term Medicaid Buy-In. She wants it changed to Freedom to Work. She believes the legislators will be more favorable to this terminology.

Fair Hearings - John commended Betty Kay for doing a really nice job for families when she testified before the Senate. John advised that Chapter 393.125 in the Florida Statute states that people have a right to a DOAH 120 hearing. There are 2 types of hearings, the DCF fair hearing and the 120 hearing which takes place before an administrative law judge. An individual felt they had a right to participate in a 120 hearing but APD objected. The case went all the way to District Court of Appeals which ruled the individual had the right to a 120 hearing. APD in turn has filed a petition before the administration commission (Governor & Cabinet) asking to ignore the court's decision and continue the fair hearing process only until at least 90 days after the upcoming legislative session. Discussion followed questioning why APD is against allowing the DOAH (120) hearing process. One reason could be that 90% of fair hearings rule in favor of APD. There are few fair hearing cases that are appealed by the family. If they do happen to appeal, every one has been overturned. John believes whatever can be done to narrow the need to expose people to this fair hearing process is a good idea. Better collaboration between APD, families, self advocates and providers would help eliminate the need. He urges the use of the reconsideration process. Statistics show that 1 out of 4 consumers had their services reduced, suspended or denied. Of that 25%, about half do the reconsideration process and of those about 60% win. The issue is resolved thus eliminating the need to pursue a fair hearing. John expressed the views of ARC Florida is the law should be followed and people should have the choice between the two. In the meantime, work closely with APD to improve the fair hearing process. John provided everyone with a copy of a summary of ARC Florida's meeting on fair hearings. It included their objectives, considerations and recommendations. He reviewed the document. John mentioned a public hearing will take place on September 25th in Tallahassee on this issue. He is asking families who have been through the fair hearing process to send him a couple of paragraphs about their experience. ARC Florida will summarize the data received and present to the Administration Commission to help them understand why they should not approve APD's petition. He is also requesting families to provide recommendations on how to change the process. He is hoping families will attend the public hearing. He mentioned what takes place next is the Administration Commission aides meet on October 11th. The actual Administration Commission meeting takes place on October 17th. Discussion followed regarding the APD's current policy of **not** sending fair hearing notices by certified mail. Many families never get the notice or by the time they do the respond time has expired. Chair Houghland asked if someone could attend the public hearing on the 25th and represent FCCFlorida. Betty Kay mentioned she would try to attend. John also mentioned that a written notice could be prepared on behalf of FCCFlorida and presented at the hearing if no one was able to attend. Ann reminded it was decided to write a letter. It needs to be presented at the hearing. Chair Houghland thanked John for attending the meeting. His time and effort is greatly appreciated.

VII. NEW BUSINESS

Quality Leadership Council conference - Chair Houghland mentioned she attended Kevin Edwards Council on Quality and Leadership 2 day conference. She said the conference was very good. She shared Kevin's views on Adult Day Training programs. He believes they should be

called what they are, not adult day training program. They are adult day care programs. Frank asked who is Kevin Edwards. Chair Houghland replied he does training and accreditations of organizations for the Council on Quality and Leadership. Ann shared CQL is very involved with Delmarva and the APD area quality leadership program. In the information packets are copies of the powerpoints that took place during the conference. She shared highlights of Kevin's presentation. The primary attendees of the conference were group home owners, some support coordinators and big agencies wanting to think about getting accreditation. Kevin was explaining they look at the people they serve. He said any organization wanting accreditation will need to prove to CQL that they have connections in the community. A connection to the community is not going bowling or traveling with other group home residents to the mall. That is not connecting to the community. Chair Houghland mentioned the second day involved more of the process involved in getting accredited. Kevin supports "caring about" the individual as compared to "caring for" the individual. Ann shared that Linda Mabile at Central Office who has the quality assurance grant has money for Kevin to give presentations throughout the state. If any FCC is considering a training or conference, Kevin would be a good speaker. Contact Linda and the grant money could cover his cost.

Year-End Report – Ann shared she has held off on completing the report to send to the legislators because she wants to include the year-end financial documentation. Bob indicated it will probably be January before that is complete as they're still working on certified forwards. Ann advised based on that news she'll go ahead and finish it.

Letters of Recommendation – Beverley shared she would like to see FCCFlorida write more letters of recommendation. She thinks the council is not exercising its power. She would like to see some sort of work group to develop a work plan for drafting of letters as a way of making our positions known. This would be helpful as a means of communicating with legislators, Shelly, the Governor and other agencies. She will offer her services as well as establishing this work group committee. The functions of the committee would be to create a schedule of issues, provide discussion, bring forth to the meeting, have area councils review, bring it back to the table and write a position. An example would be Medicaid Reform. This would make the letter writing process a more formal one and take the load off the chairperson. Chair Houghland suggested calling it a Committee to Identify Priority Issues. Maryellen has volunteered to be on the committee with Beverley.

Medicaid Reform – Ann and others voiced their concern on not hearing anymore about the DD councils Medicaid Reform project. There was one meeting but no communication since. Discussion followed providing examples of problems that have already occurred in Broward and Duval Counties when DD consumers received choice counseling materials in error, APD told them to ignore, nothing was done within the 30 days so some are now enrolled in HMO's.

Governor Appointments – Ann requested that Stephanie provide at every meeting an update on the status of FCC applications received.

VIII. CITIZENS TIME

Yellow Notebooks - Donna expressed her concerns regarding the yellow notebook training sessions, the lack of attendance because the only advertising the APD does is via websites, inaccurate notification of time change, and presenter issues. She attended the Orlando training where one family with a consumer & one Mom showed up. It's a real shame because the information in the yellow notebook is very good material and should be shared with families. Ann and Beverley suggested this should be the subject of the first letter in the new committee. Beverley asked Donna and anyone else with the same issues to write concerns and send to her. They agreed to do so.

IX. ADJOURNMENT

Chair Houghland asked to return meeting evaluations to her. The meeting was adjourned at 3:40.

The next meeting will be held on November 18th at The Hampton Inn.

RESPECTFULLY SUBMITTED,

FICD

Florida Institute on Community and Disability